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ABSTRACT

The report of the New York State Commission on Quality of Care for the Mentally Disabled looks at autism in five chapters concerned with characteristics of autism, parenting the autistic child, New York State's institutional care network for the autistic, perspectives of professionals on autism, and Commission recommendations. Among nine findings of the report are the following: the service delivery system is driven by the needs of larger and better organized groups of developmentally disabled advocates; there is no accepted theory of etiology, diagnosis, or treatment modality; parents must negotiate the maze of available services without guidance; services vary depending upon location; and there is a critical need for developing day programs for the autistic from preschool through adult age. Eight recommendations are made, only three of which would require new funding. Among the cost free recommendations are establishing the Office of Mental Retardation and Developmental Disabilities as the lead agency serving the autistic with primary responsibility and accountability for meeting their needs; to establish a State Autism Task Force as to identify, formally assess the needs of, and plan a course of service development for the autistic; and to involve parents in planning treatment and programing when possible. New funds would be required to conduct a survey to identify all service providers in the State serving and/or willing to serve the autistic; identify all individuals in the state with autism; and expand services by 100 new community residential beds for autistic individuals. Appended are addresses of five autism advocacy agencies in New York and responses of various state agencies to the Commission's report. (DB)

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THE ENDLESS QUEST:

The Autistic and Their Families

A Report by the
New York State Commission on Quality of Care
for the Mentally Disabled

August 1981

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Preface

In the fall of 1978, the Commission on Quality of Care for the Mentally Disabled held public hearings to identify priorities. At each of the four hearings conducted, the Commission heard testimony from families of autistic children about the inadequacy of services available to meet their needs. In an attempt to respond to these needs the Commission has prepared the following report which discusses the issues and problems related to providing adequate and appropriate services for the autistic and their families.

A draft of this report has been reviewed by the Office of Mental Retardation and Developmental Disabilities, the Office of Mental Health, the State Education Department, and the Department of Social Services. Each of these agencies formally responded to the report and their responses are included in Appendix B. The Commission considered each of these responses and made the changes deemed appropriate in the final report.

The findings, conclusions, and recommendations of this report reflect the unanimous opinion of the Commission and the Board of Visitors Advisory Council of the Commission. It is our hope that this report, in highlighting the needs of the autistic and the concerns of their families, will foster cooperative action of the State and voluntary agencies to respond to these needs and concerns.

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EXECUTIVE SUMMARY

The child does not look at you. He does not speak and appears, except for isolated moments, not to hear. Seemingly self-involved in a world unto himself, all the avenues for contact with others are shunned. His parents, brothers and sisters, and their friends and relatives are wary of this strange, yet strikingly handsome little boy. Special schools turn him away; the pediatrician refers his family to one specialist after another; and well-meaning friends caution his parents about becoming obsessed with the problems of this unusual child.

This child is autistic. Autism, a developmental disability usually diagnosed in early childhood, is characterized by social withdrawal, limited language development, and bizarre, yet routinized, self-stimulatory behavior. A disability without a known cause or origin, autism afflicts approximately 5,000 persons living in New York State.* About 60 percent of these persons are also diagnosed as severely mentally retarded and approximately 2,500 have severe behavioral disorders often manifested in violent self-abusive or other-directed aggressive acts. Approximately three out of four persons afflicted with autism are male.

The struggle of the families of the autistic to find adequate and appropriate services for their children, most of whom grow into adulthood, is never-ending. Just finding a program which will accept their child can involve an exhausting search. And, once placed, a new fear arises--the

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*Accurate prevalence figures for the number of individuals with autism in New York State are not presently available. This figure reflects the official estimate of the Office of Mental Retardation and Developmental Disabilities as cited in their revised New York State Plan, 1981-1984.

fear their child will be "kicked out." The child may be too disruptive for the program or he may not progress. And, again the families begin their search.

The struggle of the families of the autistic has been well-publicized. Television specials, talk shows, and popular journals have recounted the exhausting and stressful lives of these families. Yet, as testimony elicited at public hearings conducted by the Commission on Quality of Care for the Mentally Disabled in the fall of 1978 indicates, addressing the needs and concerns of the autistic individual and his family remains a largely unmet challenge.

The barriers to meeting this challenge are many and formidable. The mystery of the etiology of autism, the absence of reliable and universally accepted diagnostic criteria, together with the controversy which surrounds the choice of treatment or therapy for the autistic, confound even the most ardent advocates in specifying simple and unilateral recommendations to respond to the needs of the autistic and their families.

Recognizing both the painful search of families of the autistic to find appropriate care and treatment, and the fundamental road blocks to a simple path for these families, the Commission on Quality of Care for the Mentally Disabled identified services to the autistic and their families as a priority and has prepared this report, "The Endless Quest: The Autistic and Their Families."

Unlike many governmental reports, this report offers no definitive solutions. For, at present, there are no definitive remedies for the needs of the autistic; there are only first steps.

The report is organized in five sections:

(1) Autism: An Enigmatic Syndrome;

(2) Parenting An Autistic Child;

(3) A Look at New York State's Institutional Care Network for the Autistic;

(4) Perspectives from Professional Spokespersons on Autism;

(5) Looking Toward the Future: Mapping the First Steps.

It is the Commission's hope that this report, in highlighting the needs of the autistic and their families, will spur program development, continued research, and perhaps most importantly, a growing sensitivity to the special problems of the autistic and their families.

The major findings of this report include:

(1) The autistic are a small minority in a service delivery system that is driven by the needs of other larger and better organized groups of developmentally disabled and their families. Their special needs have been largely ignored by the system. At present, it is impossible to accurately identify the numbers of persons with classical autistic behaviors in need of services in New York State. Less than 20 percent of the estimated total autistic population of 5,000 individuals have presently been identified by the Office of Mental Retardation and Developmental Disabilities (OMRDD). The vast majority of the unidentified autistic are suspected to be either unserved or underserved by the present service delivery system.

(2) There is no accepted theory of etiology of or diagnosis for autism and therefore various treatment modalities, with varying assumptions about autism, are being used with little evidence of differences in therapeutic effectiveness, regardless of therapy chosen.

(3) The parents of an autistic child confront a service delivery system with scarce and varied services, lacking an accessible single point of entry. They are left to negotiate the maze of services, providers, philosophies and funding mechanisms without either guides or roadmaps.

(4) The services that are available vary depending upon the place of residence and there is no uniformity in the nature of the services required to be provided, when they are provided at all, nor any logical explanation for existing variations. As a result, the autistic are made to fit into existing programs, designed to meet the needs of others, rather than programs being designed to meet their individual needs.

(5) As a result of the lack of knowledge about the true prevalence of autism in the population already in the service delivery system, the tiny fraction identified and scattered throughout the system have not warranted the development of the specialized services they require. Only four of the fifty-one State facilities have developed any specialized programming for this population.

(6) Although there is significant agreement between parents and experts on the need for family involvement in programs for the autistic child to enhance their effectiveness, only three of the fifty-one State facilities provide some parent involvement as co-therapists or assistants in the programming for the autistic.

(7) Required training for professional and paraprofessional staff in programming and services for the autistic is largely nonexistent.

(8) Although four agencies (the Office of Mental Health, the Office of Mental Retardation and Developmental Disabilities, the Department of Social Services, and the State Education Department) are involved in some way with programs and services for the autistic and their families, coordination of their role is currently lacking.

(9) There is at present a critical need for developing a full range of accessible day programs for the autistic from pre-school through adult age. At the same time, it appears that additional residential placements, particularly for the adult autistic,

many of whom are currently inappropriately housed in children's psychiatric centers, are required. Additionally, respite care services for the families of the autistic are urgently needed.

These findings demonstrate the scope and seriousness of the problems inherent in the service delivery system for the autistic. By all accounts appropriate services are extremely limited and access to these services is often blocked by one or another bureaucratic barrier. The accounts of families of the inadequacy and insensitivity of the service delivery system have been substantiated by both the senior clinical staff of State facilities and reputable spokespersons in the field of autism in New York State.

As Commission staff pursued their research on services for the autistic, it became clear that these problems and issues mandate systemic change. More clearly, it became apparent that meaningful change in the service delivery system would require the joint cooperative effort of the Office of Mental Retardation and Developmental Disabilities, the Office of Mental Health, the State Education Department, and the Department of Social Services. It was also apparent that a single State agency had to be designated the lead agency for services for the autistic and that this agency must assume responsibility and accountability for services for the autistic.

Finally, it also became apparent that the State could no longer put the issue of the autistic on a "back burner". The parents and families are becoming more and more vocal in demanding responsive action to their concerns and needs. And, meanwhile the identified autistic population in need of services is growing. At present over 20 percent of the State facilities have an inpatient census of over 30 clients evidencing classical autistic behaviors. And, this population reflects only the first generation of adult autistic clients.

Given these imperatives, the Commission on Quality of Care for the Mentally Disabled offers the following recommendations for immediate State action to improve the State's service delivery network for the autistic and their families.

(1) The Office of Mental Retardation and Developmental Disabilities should be designated as the State's lead agency serving the autistic population. As such a lead agency, OMRDD should accept primary responsibility and accountability for ensuring that the service needs of the autistic and their families are met.

(2) A State Autism Task Force should be established as an ad hoc study group of the Developmental Disabilities Planning Council to identify, formally assess the needs of, and plan a course of service development, including residential and non-residential services, for the autistic. The Task Force should also address:

- the service needs and appropriate placement of the adult autistic presently in State Children's Psychiatric Centers;
- the identification of training needs for professional and para-professional staff to serve the autistic;
- the advisability of regional, residential programs for the autistic in lieu of the current dispersal of the population throughout the 51 State facilities;
- the advisability of establishing a Bureau of Autistic Services in OMRDD.

The Task Force should be chaired by OMRDD and should include representation by the Office of Mental Health, the State Education Department, the Department of Social Services, the Commission on Quality of Care, autism advocacy agencies, and parents of autistic individuals. The Task Force should be charged with reporting its findings and recommendations to the Governor within a 12-month time frame.

(3) In the development of new services for the autistic, special consideration should be given to the involvement of parents in the planning process, and in treatment planning and actual programming when they so desire.

(4) Pending the development of appropriate services for the autistic in every region of the State, OMRDD should allow families of autistic children and adults the option of admission to State-operated programs and facilities without regard for regional residency requirements.

(5) The OMRDD should seek federal funds to conduct systematic and comparable bi-annual evaluations of programs serving the autistic. The objective of collecting this evaluative data would be to determine which program models are most responsive to the needs of the autistic. The OMRDD should also continue to access available federal funds for basic research on the causes, nature, and treatment of autism.

(6) The OMRDD should conduct a survey to identify all service providers in the State serving, and/or capable and willing to serve, the autistic. Based on this survey, OMRDD should compile a consumer directory of autism service providers for families of the autistic. In addition, a toll-free hotline to assist families in their search for services should be established by the Office of Mental Retardation and Developmental Disabilities.

(7) The State Legislature should provide special funding for the OMRDD to proceed with an intensive campaign to identify individuals with autism. This campaign should rely on a taxonomy of classical autistic behaviors identified by the above Task Force and should focus on identifying autistic clients in based services. While the campaign should seek early identification of young children with autistic-like behaviors, caution should be taken not to label children prematurely as "autistic." Rather the identification should serve primarily to assist the child in accessing relevant services to meet his/her needs.

(8) The State Legislature should seriously consider the Office of Mental Retardation and Developmental Disabilities' request for start-up monies for 100 new community residential beds for autistic individuals.

Most of these recommendations can be implemented with no substantial expenditure of new money. The last three recommendations will require new funding. The funding requirements for these recommendations should be determined by OMRDD in conjunction with the State Autism Task Force.

These recommendations reflect the unanimous opinions of the Commission on Quality of Care and the Board of Visitors Advisory Council of the Commission. They are also generally consistent with the implementation of OMRDD's major program initiatives for services for the autistic as specified in their updated Five Year Plan. It is the Commission's sincere hope that the Governor and the Legislature will seriously consider these "first steps" toward building an appropriate and accessible service delivery system for the autistic.

Chapter I

AUTISM: AN ENIGMATIC SYNDROME

In an effort to gain a better understanding of the nature of autism, the theories concerning its etiology, and the philosophical premises of the various treatment approaches for the autistic, Commission staff initiated its research with an extensive review of the literature. Searching bibliographic indexes of the different disciplines, the staff reviewed nearly two hundred references. Yet, this review of existing literature raised many more questions than answers. It was the conclusion of staff that autism, indeed, is an enigmatic syndrome.

What is Autism?

Leo Kanner (1943) is credited with labeling the syndrome of autism. He described 11 children who had five essential features of what he labeled early infantile autism: (1) profound withdrawal from people; (2) obsessive desire for sameness; (3) skillful and affectionate relationships to objects; (4) retention of an intelligent and pensive physiognomy and good cognitive potential; and, (5) mutism or language problems.

Experts on autism today agree with Kanner that autism is best described as a collection of symptoms or a syndrome rather than a specific illness (Kaufman, 1976; Ritvo, 1977; Webster, 1980). Most of Kanner's basic symptoms are also accepted today, with the exception of his assertion of "good" cognitive potential. Most researchers now feel that approximately 70 percent of the individuals with autism have a subnormal, functional intelligence quotient (Newson, 1979; Ritvo, 1977; Webster, 1980).

The National Society for Autistic Children, together with other researchers, have modified slightly Kanner's basic symptomatology for autistic persons. The National Society identifies four classic symptoms:

(1) disturbances in the rate of appearance of physical, social, and language skills;

(2) abnormal responses to sensations;

(3) absent or delayed speech and language, with possible presence of specific thinking capabilities; and

(4) abnormal ways of relating to people events and objects (Ritvo, 1977).

Webster's more comprehensive, discrete list of symptoms characterizing the autistic syndrome remains generally consistent with that offered by the National Society. He lists 14 discrete symptoms: (1) autistic isolation; (2) unrelatedness to others; (3) twiddling behaviors; (4) inconsistent developmental continuity; (5) self-destructive behavior; (6) temper tantrums; (7) I/You apparent confusion; (8) concrete thinking; (9) perceptual inconsistencies; (10) echolalia - immediate and delayed; (11) orderliness; (12) physical incoordination; (13) language lacks; and, (14) excessive activity (Webster, 1980).

Though there is little debate over the general symptomatology of autism, there is considerable debate over its diagnostic criteria. Only first labeled forty years ago, autism remains a difficult disability to isolate and diagnose. The autistic individual shares many characteristics with severely emotionally ill and/or mentally retarded persons. While researchers continue to seek out ways to differentiate the autistic syndrome from mental retardation

or childhood schizophrenia (Freeman, 1978; March, 1973), others doubt the validity of the separate syndrome of autism, and still others are stymied in the development of reliable and universally accepted diagnostic criteria.

Among the problems confronting researchers seeking diagnostic criteria for autism is the wide range of functional abilities and deficits of the autistic (Kelly, 1977). More clearly, some autistic children have very high intelligence scores, while the majority score very low on intelligence measures. Some develop no language; others, often through intensive treatment, develop near normal expressive and receptive language skills. Some autistic children are very self-abusive; others never demonstrate any aggressive behavior. In sum, the syndrome of autism is marked with wide ranges of functional deficits and strengths.

At the same time, almost all autistic individuals suffer from social isolation, communication disorders, and bizarre behavioral patterns. Thus, on the one hand there appears to be the necessary likeness for a common label, and yet, simultaneously sufficient functional differentiation to preclude a single diagnosis.

Seeking the Etiology of Autism

Underlying most of the unanswered questions about autism is the absence of understanding concerning its etiology. Theoretical discussions of the genesis of autism range from the psychogenic theory to the genetic theory to organic causation theories. The range in these theories precludes any unifying position on a common etiology and some experts have even posited that autism may indeed not result from a single disorder (Webster, 1980).

The psychogenic theory of the etiology of autism suggests that the disabilities of the autistic child result from early deficits in the parent-infant relationship. In the past decade this theory has fallen into disrepute largely due to the fact that few researchers have been able to identify significant differences between mothers of autistic children and mothers of other severely disabled children (Cantwell, 1979; Friedman, 1974; Lennox, 1977; McAdoo, 1977; Schopler, 1979).

Yet, some researchers continue to emphasize the psychogenic etiology of autism citing the substantial parallels in insufficient and deviant ego development in the autistic and schizophrenic individuals (Bettleheim, 1967; Mahler, 1962; Roth, 1972; Tustin, 1972). In general, however, there appears to be sufficient evidence to cast doubt on the theory that inadequate parenting is the primary cause of the symptomatology of the autistic individual.

Other researchers on autism raise the possibility of a genetic, rather than psychogenic etiology. These researchers, relying primarily on the unusually high prevalence of autistic children in families with other autistic children or with a history of psychiatric disorders, as well as the higher prevalence rate of autism among males and in families in the upper-middle class, suggest that autism is transmitted genetically (Science News, 1978; Yahres, 1978). This theory, like the psychogenic theory, also lacks sufficient hard data to substantiate it. Rutter's statement in 1968, "The role of genetic factors [in autism] remains unknown," continues to be true today.

With most experts at odds with either the psychogenic or genetic causation theories of autism, it is not surprising that most current research on the etiology of autism

focuses on organic causation theories. Strong support for the organic causation theories derives, at least in part, from the high incidence of a medical history of more complications just before, during, or just after birth (Newson, 1979). In addition, about one-third of the diagnosed cases of autism have associated gross neurological abnormalities (spasticity or epilepsy). Finally, there is also evidence that congenital rubella may also lead to autism.

Some groups, most notably the National Society for Autistic Children, have formally adopted a position that autism results from a physical dysfunction within the central nervous system (CNS) (Gray, 1978; Ritvo and Freeman, 1978). However, like the above two theories, the lack of firm evidence to substantiate dysfunction of CNS as a cause makes this assertion less than certain. Rutter's comment on this theory is also relevant,

> The role of brain damage in the genesis of autism is also uncertain, but organic brain abnormalities appear to be primary influences in some cases--in how many is not known. In any case, the concept of brain damage is too general to be of much help in understanding the genesis of autism (Rutter, 1968).

Other organic theories of the etiology of autism have also been posited. These theorists have sought to identify significantly variant physiological abnormalities in persons with autism. Yahres (1978) suggested that the symptoms of autism may arise from dysfunctions in the body's system for regulating the state of arousal and attention. Maher's research with a small sample of four 13-year-old autistic children supports Yahres' hypothesis in finding abnormalities in endocrine response to insulin stress in these subjects (Maher, 1975). Similarly, Dr. Donald Cohen suggested that autistic individuals may have over-active

dopamine systems and that treatment with haloperidol and phenothiazines, which inhibit dopamine action, have therapeutic benefits (cited in Yahres, 1978). Yet, like the other theories of the genesis of autism, the determination of the relevance of abnormalities in physiological arousal awaits further research.

In summary, just as there exists no accepted set of diagnostic criteria for autism, there exists no strong basis in research for the etiology of autism. The fact that one or another theory of the etiology of autism is sometimes supported in one sample and not another, and that other theories, despite their mutually exclusive logical basis, may be supported coterminously continues to confound efforts to identify a single predominant etiology. Perhaps, the search for a predominant etiology is itself without a cause. The above discussion of the variance in functional deficits among the autistic may, in fact, lend more credence to the acceptability of multiple theories of the genesis of autism.

Seeking Appropriate Treatment: An Agonizing Game of Hide and Seek

The conflicting points of view regarding the etiology of autism have severe consequences for the evolution of appropriate treatment models. The conflict among current treatment modalities, from psychoanalytic therapy to behavior modification to educational programming to psychopharmocological interventions to other forms of chemotherapy, arise in a fundamental way from the different theories of the genesis of autism (Mulcahy, 1972). And, perhaps more importantly, there exists little evidence of differences in therapeutic effectiveness regardless of the therapy chosen (Webster, 1980; Wenar, 1976).

Given this range in therapeutic interventions, it is not surprising that parents of autistic children soon become disaffected and frustrated with the professionals who toss their child from one therapy to another. These families soon come not to trust any expert on autism, and instead are forced to rely on their own best instincts. The saga of the Kaufman family is typical,

> We had talks with doctors and hospitals in and around New York City. We queried an institute in Philadelphia specializing in brain damaged and autistic children. There were specialized environmental schools, one in Brooklyn and one in Nassau County, neither of which would see our child until he was much older--and even then it would be a maybe. We contacted a dedicated specialist in behaviorism in California with a major university and a Federal grant to study and research autism. We investigated psychopharmacology. Psychoanalysis. Behaviorism. Vitamin therapy. Nutritional analysis. The CNS factor. The genetic theory. There were many opinions and non-opinions, many unsubstantiated theories and debatable assumptions (Kaufman, 1976, emphasis added).

This endless search for appropriate treatment would be less devastating if the available approaches were not so substantively different. Each has its own assumptions about the autistic person and the etiology of his/her autism; assumptions which tend to be mutually exclusive with other approaches. Jerome highlights these classic dialectics in the treatment approaches for autism as: (1) stress versus protectiveness in the child's environment; (2) entering into the child's fantasies and feelings versus making reality demands and limitations on him; and, (3) reinforcing behaviors through rewards versus relationships (Jerome, 1973).

The conflicting assumptions underlying treatment approaches for the autistic are most evident in the contrasting assumptions of the psychoanalytic approach and the behavior modification approach. In the former, a primary emphasis is placed on building sufficient trust in the child so he/she will break out of his self-involved world. This therapy accepts the child's fantasies, stresses a protective environment, and emphasizes the primary goal of building an interpersonal relationship. Kaufman's comments are central to the psychoanalytic approach,

> We decided that his 'isms' (the ritual behavior of rocking, spinning, finger flapping and so on) were perfectly okay with us. In fact, as a result of our initial observations, we sensed that his 'isms' were tools that he used to make sense out of a complex and bizarre confusion of perceptions. Perhaps, they were his healthy way of coping (Kaufman, 1976).

The behavior modification approach, on the other hand, hardly takes cognizance of the child's fantasies. There is much less concern with why the autistic client retreats inward. Instead this approach seeks simply to motivate appropriate behavior through rewards and, sometimes, to extinguish inappropriate behaviors through punishment. Although critics of the behavior modification approach criticize its disregard for the dignity of the child (Kaufman, 1976), its proponents point to significant progress in the client (Ferinden, 1973; Hobbs, 1977; Koegel, 1979; Palyo, 1979; Schrubman, 1975). Advocates of the behavior modification approach generally adhere to the CNS disorder theory of the genesis of autism and argue that this approach helps to motivate the autistic child and assists him/her in concept formation, a critical variable to language development. Critical to the behavior modification approach is the principle of generalization, or the principle that if a child learns specific facts and skills under

the reinforcement circumstances that he will be able to generalize what he has learned to other circumstances. Critics of this approach argue that the goal of generalization is rarely achieved outside the therapy setting (Delacato, 1974).

In general, the greatest success of behavior modification programs lies in their ability to stimulate language development and to inhibit self-abusive and other-aggressive behaviors (Ferinden, 1973; Lovaas, 1974). The literature cites a lack of transfer of learned behaviors to outside the therapy situation and the limited social growth as the major weaknesses of this approach. Behavior modification therapies also tend to be slow, laborious therapies. At the same time, there are more evaluation studies supporting this approach than any of the others. This support, however, may be due more to the relative ease of assessing the behavioral modification setting over the other approaches.

The educational approach to treatment for the autistic is similar to the behavior modification approach. Like the behaviorists, these clinicians believe that autism derives from a CNS disorder (Fenichel, 1974). Also like the behaviorist, proponents of educational therapy attempt to restructure the autistic client's environment to encourage him/her to make the appropriate learned response (Sloan, 1977). The major difference between the two approaches is the education treatment's greater emphasis on the content of what is learned. The behaviorist, more clearly, is chiefly interested in establishing a pattern of learning or changed behaviors, while the educator is primarily interested not in the pattern of learning, but also what is learned. As a result, the educational approach relies heavily on individualized, highly sequenced curricula (Fenichel, 1974; Delacato, 1974).

The other major treatment interventions include psychopharmacological interventions and other chemotherapies. Though none of these therapies have substantial evidence supporting their use, they remain a major focus of treatment interventions. It appears from the literature that everything from phenothiazines to vitamin B-6, to L-5 Hydroxytryptophan to hallucinogens have had some success in treating some autistic patients (Abbassi, 1978; Campbell, 1978; Rhead, 1977; Sverd, 1978). What is less clear is why these substances work. Also unknown at this time, is whether they would be shown effective in more stringent experimental tests with a larger sample of clients.

The psychoanalytic, the behavior modification, the educational, and the biochemical treatment interventions constitute the major treatment approaches for autism and provide a reasonable sample of the diversity among the therapeutic remedies offered to the autistic. Yet, these approaches are accompanied by a vast number of less-recognized treatment interventions, including, but not limited to: play therapy, garden therapy, art therapy, music therapy, gesture therapy, and structural therapy. These "minor" league interventions in the treatment game for autism are unlike the major league players in that they are characterized chiefly by the medium of the therapy rather than by their fundamental etiological assumption about the autistic syndrome.

More simply, art, music, or gesture therapy each use a different medium to enhance communication skills. Yet, each can be adapted to either the behaviorist or psychoanalytic school depending upon the therapist's means of utilizing the medium. Of these minor therapies music therapy (Hollander, 1974; Hudson, 1973; Mahlberg, 1973; Saperston, 1973) and gesture therapy (Konstantareas, 1977a, 1977b; Stull, 1979;

Webster, 1973), both of which focus on improving communication skills, appear from the literature to offer the most promise. In general, however, the rigor of the research asserting the effectiveness of any of these "minor" interventions is wanting.

In discussing the great variance in treatment approaches for the autistic, it is easy to lose sight of their common attributes. Specifically, most all therapeutic interventions focus on three common goals: (1) increasing the client's motivation; (2) enhancing the client's communication skills; and, (3) improving the client's social behavior. Many of the different therapies also place a similar emphasis on a carefully planned environmental setting, the permanence of the therapist and, in the case of all except the psychoanalytic modality, the involvement of the parent as co-therapist.

Thus, despite their substantial differences the many treatment interventions also share significant commonalities. This fact, together with seemingly incongruence of "success" stories resulting from almost every treatment modality, has led some researchers to suggest that people succeed with the autistic through their genuine interest, concern, and commitment rather than through the efficacy of any one theoretical intervention (Webster, 1980).

Conclusion

The literature allows for few conclusive statements about the mystery of the autistic syndrome. Its diagnosis, etiology and treatment continue to raise questions even among the most noted scholars in the field. What is known about autism is limited to a few basic facts:

(1) Children with autism appear to have serious developmental lags in physical, social, and language development;

(2) The functional impact of autism varies considerably among the afflicted population;

(3) Among the many posited etiologies of autism, none are fully substantiated and it appears probable that the genesis of autism may not result from a single cause or disorder; and

(4) Treatment approaches to autism are many and strikingly differentiated. It appears that the underlying commonalities among different approaches--permanence of the therapist, a highly structured environment, and involvement of parents--may be the significant guidelines for effective programs.

Chapter II

PARENTING AN AUTISTIC CHILD

Once accused by most professionals, and still accused by some, of being the cause of their children's autism, parents of autistic children until recently have largely endured their struggles alone. Like Clara Park, Elly's mother, most do not seek to broadcast their problems.

> Elly had been in a private school from [age] 5 to 8 - nursery and kindergarten. Then they wouldn't keep her and I took her to the public school superintendent's office. I had hoped not to have to do it; I had hoped to keep our private disaster from being a public burden (Park, 1974).

Today, parents of autistic children are increasingly "speaking out" - voicing their concerns, needs and demands. They have joined together in groups; they have learned about the power of advocacy.

In the course of this study, Commission staff sought to better understand the concerns, needs and demands of these families. Staff read many personal accounts of families of autistic children and conducted lengthy interviews with three of these families.

During this process, Commission staff became very close to these parents. Indeed, it was difficult not to identify with their needs and concerns. As for their demands, they seemed small in comparison to the damages wreaked upon them by an inadequate and, often insensitive, service delivery system. This chapter reports on what we learned from the parents of autistic children.

Being a Parent of an Autistic Child

Being a parent of an autistic child has been alternately described in the literature as being like a hostage of a hijacker or as being like a saint of unlimited patience, caring, and giving (Kaufman, 1976; Tomaro, 1972; Torisky, 1978). Both descriptions have only metaphoric validity. Yet, if parenting a normal child can be an exhausting task, then parenting an autistic child can be an exhaustive search.

Parents of autistic children usually realize something is wrong with their child in early infancy; and almost all know something is drastically wrong by their child's third birthday. At this point, these parents begin their search for help. Many turn first to their family doctor. But neither family practitioners nor pediatricians typically have much help to offer and the parents search on. For many the search never ends. Kaufman writes of the parents' frustration and despair that soon settles in,

> After contacting the National Society for Autistic Children and talking with parents of children similar to ours, we found that most had initiated a search for information and advice and received little or no help. In many instances, they learned to accept their predicaments with varying degrees of despair and frustration (Kaufman, 1976).

Even as these parents do sometimes find an acceptable program for their child, a new fear arrives. Experience has taught them that their children may be "kicked out" of the new found program shortly after they are enrolled. Clara Park describes her anguish when her daughter, Elly, was "kicked out" of a program for being too disruptive and of having to endure "five awful months of no school program" (Park, 1974). Still another concern of parents as their child starts a new program is their fear of the program

itself. Webster writes of this fear, "What will be required of him...! Although they [parents] are not likely to say it in so many words, they are trusting that the child's life will not be made any more anxious and bewildering than it already is (Webster, 1980)."

Most parents of autistic children soon become alienated from the so-called "helping" professionals. They recount how one educational and mental hygiene agency after another sent them away because their child simply did not fit into a program (Webster, 1980). One father describes his experiences with professionals as "a dance in the hallowed halls of medicine (Kaufman, 1976)." Another father expresses his alienation from the "helping" professionals more vividly,

> We were in the position where the professionals were God. And looking back on it, the professionals viewed us as simply uninstitutionalized people! That's all. They were right, we knew nothing about it, and when we said, "You're not talking about the right person, ours is a girl not a boy," he ignored that because we were simply uninstitutionalized adults (Webster, 1980).

All the anger and frustration of parents of autistic children is not directed toward others, however. Most have many painful moments of self-doubt and despair. Most parents of autistic children sometimes search for a fantasy exit from their struggles. The comments of one mother are reflective of this painful fantasy,

> ...and I would sit and pray for seven o'clock to come and I'd really pray, and I'd put that child to bed and I would say to myself, "Tomorrow is going to be just like today...and how am I going to live this way because to me life is just impossible. I just have no joy from this child at all. I have no reward...". But every night I would think this and I would say, "I'm wishing his life away - he is going to be an old man and here I am praying that seven o'clock will come for bedtime" (Webster, 1980).

One of the ways autistic parents have learned to deal with their frustration and despair has been to become very involved in advocacy efforts for the autistic and in their child's treatment program. In New York State dedicated advocacy efforts on behalf of autistic children were initiated in the late '50s. One of the first such grcups was the League for Emotionally Disturbed Children. Gradually other advocacy groups evolved to promote treatment and educational services for the autistic. These groups have included, among others, the Nassau Center for the Emotionally Disturbed (now called the Nassau Center for the Developmentally Disabled), the New York Society for Autistic Children, Services for Treatment of Autism Respite and Research (S.T.A.R.R.), Help Autistic People Please, Inc. (HAPPI), and Special Citizens Futures Unlimited. (See Appendix A for listing of the addresses and contact persons of these agencies.) These groups, composed almost exclusively of parents, have, in addition to promoting services for the autistic, also fostered legislative proposals to enhance the funding and development of program services and sponsored community education efforts to inform the public of the nature of autism and the needs of autistic people.

Over the years these parent advocacy groups have become very well-informed about autism and the complex issues related to its diagnosis and treatment. Many of the parents active in these groups have both formally and informally sought to share this knowledge of the field with professionals. Indeed, partially due to the relative lack of knowledge of professionals in the field, parents have increasingly served as guides for the professionals. In recent years, programs have come to take greater and greater advantage of the valuable resources of parents (Parents as Co-Therapists, 1979). These programs have sought to utilize parents as a vital part of the treatment team in the planning and delivery of services.

The recognition that parents can be very effective co-therapists, especially in the behavior modification treatment setting, has brought increased parent involvement in programming (Brown, 1969; Kozloft, 1973; Marcus, 1978; Nordquist, 1973; Sloan, 1977). At times, parents have even been shown to be more effective than the professionals. And, most all programs utilizing parents as co-therapists have demonstrated that parent involvement increases the transfer of learned behavior change outside of therapeutic milieu (Kelly, 1977; Parents as Co-Therapists, 1979). Indeed, perhaps the most convincing reason why parents have been successful in the therapy setting is their ability to reinforce learned behaviors in the therapy milieu in their daily interactions with their children.

In summary, the experience of being a parent of an autistic child can be a painful and frustrating ordeal. Yet despite this ordeal, many parents of autistic children have taken on an active role in guiding and participating in their child's programming. For these parents, this involvement has not only proven to be beneficial for their child, but it also has made their role as parents more satisfying.

Unmet Needs: The Families Perspective

Families of autistic children are becoming more and more vocal about the unmet service needs of their children. As mentioned above, more and more families are becoming active in program efforts with their children. And, as they see one program work, they become more ardent advocates for others.

To learn more about the specific concerns and needs of families of autistic children, Commission staff interviewed three of these parents. These parents were referred to the Commission by advocacy agencies for the autistic and all had

been active in the autism advocacy movement. As such they may not be representative of all parents of autistic children. At the same time the unanimity in the issues raised and the views expressed suggest a certain reliability in their responses.

In general, these parents had concerns and needs related to four broad issues:

- the limited services for the autistic and particularly the autistic adult;
- the bureaucratic morass of State agencies involved in the care and treatment of the autistic; and
- the ineffectiveness of most diagnostic services in detecting autism at an early age;
- the need to strengthen advocacy and community education efforts on behalf of the autistic.

Of these four issues, the one which concerned parents most, not surprisingly, was the lack of services. They emphasized that while services are lacking in almost every area of treatment for almost all autistic persons, services are especially lacking for the autistic adult. These parents also took strong exception to the State's decertification of out-of-state residential programs. The need for 12-month programming, as well as respite services for the parents of the autistic child living at home were cited.

Parents also spoke of the lack of continuity of services. One parent complained specifically of the funding and administrative instability of programs. Another perceived the bureaucratic morass of State agencies as contributing both to the lack of continuity of programming and to the tiring search to find adequate programming.

Among the other major concerns and needs of these parents of autistic children was more effective diagnostic services for autism. One parent's comment was typical, "Many professionals know little or nothing about autism.

This prevents early identification and subsequent treatment." Another parent voiced concern about the proposed State Education Department initiative not to use the autistic label. This parent feared that the absence of labels may in the long run inhibit the autistic child's access to services. All the parents interviewed saw considerable problems in great variance of diagnoses by different professionals for the same child.

Finally, these parents all spoke of the need to strengthen and unify the advocacy agencies for the autistic. One parent specifically called for networking the regional advocacy efforts to form effective statewide organizations. These parents quite accurately perceive a strong advocacy movement as a means for pressing for greater State responsibility and accountability for effective diagnostic, residential and treatment services for the autistic.

Moving Ahead: Recommendations to Improve Care

During their interviews, these parents also made many recommendations to improve the care and treatment for their autistic children. Generally, these recommendations were closely aligned with the parents' perceptions of unmet needs and, therefore, are well stated above. However, the many recommendations which focused on systems change deserve some attention.

In general, these parents voiced a strong concern that the State's present means of providing services to the autistic through four essentially non-cooperating agencies was ineffective and allowed no accountability. Specifically, parents asked for more cooperation and coordination among the Office of Mental Health (OMH), the Office of Mental Retardation and Developmental Disabilities (OMRDD), the Department of Social Services (DSS), and the State Education Department (SED). The parents also raised the

recommendation that services for the autistic should have their own line in the budget, that overall funding for services for the autistic should be increased, and that access routes to these funds be streamlined to enhance more rapid development of services.

These parents also made two other recommendations to improve the autistic individuals' access to services. One parent urged that the State be more flexible in its certification of out-of-state programs, especially where in-State programs are few and ineffective. Another recommendation sought to eliminate the regional restrictions for program admissions for the autistic. This parent felt that such restrictions unduly discriminated against some autistic individual solely on the basis of their place of residence.

Conclusion

In conclusion, it appears that parents of autistic children have only just begun to speak out for the rights of their children. In some ways these parents know more about the autistic than the "so-called" professionals. Their desire for an improved treatment network for their children is growing and their articulation of their concerns and needs is becoming increasingly sophisticated. They recognize, for example, that simply one or two or even a dozen new programs will not address their concerns. They perceive quite accurately the need for "systems change" if the real issues are to be addressed.

Chapter III

A LOOK AT NEW YORK STATE'S INSTITUTIONAL CARE NETWORK FOR THE AUTISTIC

Meeting the service needs of the autistic population is a difficult and costly task. For the vast majority of this population, a high level of services is required from early childhood throughout their adult lives. Many, if not most, parents of autistic children first seek services for their children from community-based voluntary agencies. But these voluntary-sponsored programs for the autistic are few and far between. By the time the autistic child has reached adolescence, the family has usually run out of options and turns to the State's institutional network of care.

In conjunction with this study, the Commission on Quality of Care sought to find out what parents and families find when they take this turn. More specifically, the Commission wanted to know how well equipped State psychiatric, children's psychiatric, and developmental centers are to serve the autistic, and especially the autistic adult.

The findings of the Commission's review are disheartening. Despite the fact that over 60 percent of the facilities surveyed indicated that they serve clients with classical autistic symptoms, fewer than 10 percent offer specialized programs for this population. Perhaps even more disheartening, is the litany of unmet needs of the autistic and the barriers to specialized program development for the autistic that the facilities' representatives perceived. This chapter reports on the Commission's review of the capability of New York State's institutional network to care for and treat individuals with autism.

Methodology of the Survey

The Commission's survey of the State facilities' capability to serve the autistic was conducted via telephone interview with senior facility staff. In most cases the clinical deputy director was interviewed, but in some cases he/she referred the interviewer to the facility director, unit chief, or other senior staff. Of the 51 State facilities (25 psychiatric, 6 children's psychiatric, and 20 developmental centers), 46 responded to the Commission's survey. Of the five which did not respond, three were psychiatric centers and one was a developmental center.[1]

To ensure reliability and uniformity of the information solicited from facilities, a structured interview instrument was used to conduct the interviews. This instrument sought information about:

(1) the size and nature of the autistic population served;

(2) the nature of the inpatient and outpatient services offered to the autistic;

(3) the nature of services offered to families of the autistic;

(4) the unmet needs of the autistic in their catchment area;

(5) the barriers inhibiting the State from addressing the unmet needs of the autistic; and

(6) the facility's recommendations for State action to improve the care and treatment offered the autistic.

The findings of the survey are reported in each of these categories.

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[1]The five facilities which did not respond to the Commission's survey were: Wassaic Developmental Center, Capital District Psychiatric Center, Central Islip Psychiatric Center, Kingsboro Psychiatric Center, and New York State Psychiatric Institute.

Size and Nature of the Autistic Population Served

The first question asked by the interviewer focused on the size and nature of the autistic population served by the facility. Most facilities had a great deal of difficulty approximating their census of patients evidencing classical autistic behaviors. Developmental centers, the facilities with primary jurisdiction for the autistic, especially found this question difficult as the New York State Office of Mental Retardation and Developmental Disabilities' present patient profile forms do not allow for the recording of an autistic diagnosis.

Many State psychiatric centers' representatives also indicated that they do not use the label of autism, since they view autism as a childhood diagnosis and they serve only adults.

Of the senior clinical staff of developmental centers, three could not provide any count of their autistic population. And 9 of the 22 representatives of psychiatric centers indicated that autism, in their view, was a childhood diagnosis and that since they serve only adults, they have no patients evidencing classical autistic behaviors.

Clinical directors of the rest of the facilities surveyed, which represented only three-fourths of the original sample of 46 facilities, however, did provide Commission staff with approximations of their autistic client census. The tentative nature of these figures should be emphasized. It should also be noted that these figures are probably low rather than high, and that they reflect the autistic client census in only 31 of the total of 51 State psychiatric, children's psychiatric, and developmental centers. These figures are reported in Table 1.

Table 1: Approximate Patient Census of State Facilities Evidencing Classical Autistic Behaviors and Having a Primary Diagnosis of Autism

Autism Category	Total	Psychiatric Centers	Children's Psychiatric Centers	Developmental Centers
Total	961	107	136	718
Inpatient census evidencing classical autistic behaviors	668	102	113	453
Adults	384	92	46	246
Children	284	10	67	207
Inpatient census with a primary diagnosis of autism	40*	14*	18*	8*
Adults	20	5	14	1
Children	20	9	4	7
Outpatient census evidencing classical autistic behaviors	293	5	23	265

*The subtotal of patients with a primary diagnosis of autism are not counted in the Total figure as they represent a double count of inpatients with classical autistic behaviors.

Table 1 indicates that State facilities serve approximately 1,000 inpatients and outpatients with classical autistic behaviors. Almost 70 percent of this census are treated on an inpatient basis and are clients of State developmental centers. Interestingly, although psychiatric and children's psychiatric centers serve very few outpatients who evidence classical autistic symptoms, each serve over 100 autistic-like inpatients. Also worthy of noting is the large inpatient census of autistic adults in State facilities. Autistic adults comprise 57 percent of the inpatient autistic census.

Nature of the Services Offered to the Autistic

The Commission also sought to identify any special programs the State facilities offered for their autistic population on an inpatient or outpatient basis. By "special programs" the Commission meant programs designed specifically for the autistic. More clearly, the Commission sought to determine if facilities were providing anything different in terms of treatment and/or habilitation for their autistic population.

The Commission found that only four facilities offered specialized programming for their autistic inpatients and that only three offered specialized programming for their autistic outpatients.

Among the specialized inpatient programs was Marcy Psychiatric Center's Cranehill Unit which offers a developmental program geared to the autistic and other disabled children. This program offers very basic training in ADL (activities of daily living) skills and sign language. A special program at Queens Children's Psychiatric Center also focuses on ADL skills, relying heavily on a behavior modification treatment modality.

The special inpatient programs at both Rockland Children's and O.D. Heck Developmental Centers stand out as offering a range of programming from special education to recreation therapy to occupational therapy. In addition, the Rockland Children's program places a heavy emphasis on socialization skills.

In terms of outpatient programming only 3 psychiatric centers (out of 25), 2 children's psychiatric centers (out of 6), and 8 developmental centers (out of 20) indicated that they provided outpatient programs for the autistic. For the most part, these were not "special programs," but programs offered in their regular range of outpatient services. These programs included day treatment, a nursery pre-school group, supportive behavior therapy, chemotherapy, respite services, home evaluation teams, an after-school and weekend program, special education and an early screening program. Perhaps the most startling aspect of this array of outpatient services is the great variance in the type of service provision among facilities. No two facilities which offer outpatient services offer the same services. In addition, only in three centers (two children's psychiatric centers and one developmental center) were these services developed specifically for the autistic and, at no facility were a full range of services offered. Finally, it should also be noted that this variance in services offered to the autistic does not appear to be related to differences in the autistic population of the area or other community resources available to the autistic.

Services to Families of the Autistic

The Commission's review of the literature and interviews with families of the autistic highlighted the needs of

these families for special attention in the treatment setting. More specifically, parents of autistic individuals seem to be asking for an active role in the care and treatment of their children and demanding an end to their identification as being part of their children's problems.

With these points in mind, Commission staff asked each facility what services they provided for families. Of the 14 facilities which indicated that they offered something special for families of the autistic, the core service for 10 of these facilities (all psychiatric and children's psychiatric facilities) was some form of family therapy, support group or counseling. Two of the children's psychiatric centers, Rockland and Queens Children's, also provided home visit teams. The latter facility's nursery program, which was cited above, also involved parents in programming.

The developmental centers generally indicated that families of the autistic were not addressed separately from their general service provision for clients' families. Four developmental centers did, however, offer some specialized services for the families of the autistic. These included O.D. Heck which involves parents on an advisory board which meets monthly, and Monroe Developmental Center which offers parent training. Staten Island Developmental Center attempts to offer families some professional services (e.g., psychological evaluations) and Syracuse Developmental Center offers follow-up nursing services.

In sum, few facilities provide specialized services to meet the needs of families of the autistic. And, more importantly, those that do offer services tend to offer counseling or therapy, the service most parents of autistic individuals shun. Only three centers provide for parent involvement in program or program planning, despite the substantial evidence in the literature supporting the use of parents as co-therapists in habilitation programs for the autistic.

Unmet Needs of the Autistic

In their interviews with clinical deputy directors or other senior facility staff, Commission staff also solicited these individuals' perceptions of the unmet needs of the autistic in their catchment area. This question brought a myriad of responses, but most focused on five issues:

- the need for better, more accurate, and earlier diagnostic services;
- the need for more day program services for all age groups and all functional levels;
- the need for more long-term residential services;
- the need for respite services; and
- the need for more specially trained staff.

Table 2 relates the frequency of these responses by facilities.

Fifteen facilities' representatives cited a need for better, more accurate, and earlier diagnostic services for the autistic. There appeared to be agreement among the psychiatric center senior staff and the developmental center senior staff that the failure to diagnose the autistic individual leads to a lack of understanding of their needs which eventually inhibits appropriate program development. The developmental centers' representatives also viewed the lack of clarity of the autistic clients' mental health needs and developmental needs as a problem. Generally, the developmental centers' representatives implied that they were uncomfortable in making the autism diagnosis. Similarly, several psychiatric centers' representatives frankly admitted a certain degree of ignorance about an "autistic" diagnosis particularly as it related to a developmental disability.

Table 2: Unmet Needs of the Autistic as Perceived by Senior Facility Staff at State Psychiatric, Children's Psychiatric, and Developmental Centers

Unmet Needs of the Autistic	Total	Psychiatric Centers	Children's Psychiatric Centers	Developmental Centers
Day programs development for all ages across all functional levels	20/51	5/25 Elmira Manhattan Marcy Mid-Hudson Rockland	5/6 Bronx Children's Rockland Children's Queens Children's Sagamore Children's Western New York Children's	10/20 Bernard Fineson Bronx Broome Manhattan Monroe Rome Staten Island Suffolk Syracuse West Seneca
Residential programs long-term for all ages	14/51	2/25 Richard M. Hutchings Rochester	5/6 Bronx Children's Manhattan Children's Rockland Children's Sagamore Children's Western New York Children's	7/20 Bronx Craig Monroe O.D. Heck Suffolk Syracuse Westchester
Better, more accurate, and earlier diagnostic services	14/51	4/25 Binghamton Creedmoor Mid-Hudson Middletown	-	10/20 Bronx Broome Brooklyn Craig J.N.Adams Monroe Newark Rome West Seneca Westchester
More specially trained staff	8/51	5/25 Elmira Manhattan Marcy Mid-Hudson Rockland	-	3/20 Newark Suffolk Wilton
Respite services	3/51	-	-	Syracuse West Seneca Westchester

In terms of service development needs, the greatest need was perceived to be the area of day programming. Day programs for all age groups and all functional levels were seen as a pressing need by 20 facilities, 5 psychiatric centers, 5 children's psychiatric centers, and 10 developmental centers. These facilities' representatives saw a need for the full range of day programming from day treatment to day training to educational to vocational programs. They also perceived a need for these programs to be made available to the very young pre-school autistic population, as well as the aging adult autistic population.

Residential services are also perceived to be in great need for the autistic population. Fourteen of the 46 facility representatives interviewed raised the issue of more residential care services. Among these representatives there appeared to be less concern where the beds were (i.e., in institutions or community-based) than that more residential bed space would be made available. This was an especially serious concern of the children's psychiatric centers, with five of the six centers raising this need. This concern, no doubt, reflects the significant population of adult autistic clients presently residing in children's psychiatric centers.

The need for respite services was noted by only three developmental centers, Syracuse, West Seneca, and Westchester. This was a somewhat surprising finding in light of the fact that few centers presently have sufficient resources to provide respite for the parents of autistic individuals and that all the families interviewed by Commission staff viewed this service as being vital.

More staff training to assist facility personnel in caring and treating the autistic was cited as a need by eight facilities, five psychiatric centers and three developmental centers. The literature on autism, reviewed by Commission staff, also supports the position that personnel working with the autistic can benefit from specialized training.

Finally, it is interesting to note that only two facilities, Broome and Westchester Developmental Centers, perceived services to families to be a significant need. This is a puzzling finding in view of the feelings of families presented in the previous chapter.

In summary, the Commission's survey of facilities' representatives' perceptions of the unmet needs of the autistic in their catchment area indicates a clear awareness that the autistic are substantially underserved. Generally, these representatives saw needs in the area of diagnostic services and day programming and residential services.

Barriers to Meeting the Needs of the Autistic

Commission staff also asked the facilities' senior staff representatives what they perceived to be the major barriers to meeting the unmet needs of the autistic. In response to this question the senior staff personnel most often answered funding and the lack of identification of the population. Fifteen facilities, including five psychiatric centers, three children's psychiatric centers, and seven developmental centers, cited funding as a major barrier. The inability to identify the population through accepted diagnostic criteria was seen as a major barrier primarily by developmental centers' representatives. Ten developmental centers' representatives and one children's psychiatric center cited accurate identification of the autistic population and its needs as a major barrier.

Another barrier perceived by seven facilities (four psychiatric and three developmental centers) was staffing. The staffing barriers ranged from inadequate staffing levels to low staff morale and/or motivation to poor staff training. Another barrier that was cited notably by nearly one-third of the developmental center representatives was a lack of knowledge and agreement about the disability. Another closely related issue, difficulty in treatment, was cited by two psychiatric centers, one children's psychiatric center, and one developmental center.

Other barriers raised by one or two facility representative(s) included: (1) community resistance to residential programs for severely disabled individuals; (2) OMRDD's lack of preparation and cooperation; (3) competition between children's psychiatric centers and developmental centers for placements; and, (4) no coordinated advocacy group. Table 3 relates the barriers perceived by type of facility responding.

Making the State System More Responsive to the Autistic

Commission staff closed their interviews with the clinical deputy directors or their designee by asking what should be done to make the State facilities more responsive to the needs of the autistic and their families. This question elicited a wide range of responses, but three recommendations were cited most frequently:

(1) Initiating a statewide campaign to identify the autistic population and their needs;

(2) Development of a range of day and residential treatment program for the autistic; and

(3) Making more funds available for the treatment and care of the autistic.

Each of these recommendations was cited by at least 16 facilities out of the possible 51.

Table 3: Senior Facility Staff's Perceived Barriers to Addressing the Unmet Needs of the Autistic by Type of Facility

Perceived Barriers to addressing the Unmet Needs of Autistic	Total	Psychiatric Centers	Children's Psychiatric Centers	Developmental Centers
1. Funding	15/51	5/25	3/6	7/20
2. Lack of identification of the population and their needs (including problems with diagnosis)	11/51	-	1/6	10/20
3. Staffing	7/51	4/25	-	3/20
4. Lack of knowledge and agreement about the disability	6/51	-	-	6/20
5. Difficulty in treating	4/51	2/25	1/6	1/20
6. OMRDD's lack of preparation and coordination	2/51	-	2/6	-
7. Community resistance	1/51	1/25	-	-
8. Competition between children's psychiatric centers and developmental centers for placements	1/51	-	1/6	-
9. No central coordinating advocacy body until NYSSAC (New York State Society for Autistic Children)	1/51	-	-	1/20
10. No barriers	1/51	1/25	-	-

Two other recommendations were offered by seven or eight facilities, respectively:

(1) Provision of more support services to families; and

(2) Specialized training programs for professional and para-professionals working with the autistic.

The following recommendations were suggested by three or fewer facilities:

(1) OMRDD should work more closely with the State Education Department in planning day programs for the autistic;

(2) The available community-based programs should be surveyed and evaluated;

(3) Development of a statewide information and referral program for the autistic;

(4) OMRDD and OMH should work more closely with each other and the State Department of Social Services in seeking and making community placements for the autistic;

(5) Provide for higher staffing ratios for State-operated and voluntary-operated programs for the autistic;

(6) Work more closely with the New York State Society for Autistic Children.

In regard to the above recommendations, the issue of the multiple and uncoordinated involvement of State agencies surfaced most frequently. This multiple involvement reflects the overlapping responsibilities of OMRDD, OMH, SED, and DSS for serving the autistic. Each of these agencies certify programs and facilities which serve the autistic. More clearly, OMH and OMRDD both certify day and residential treatment programs for the autistic, SED certifies both in-State and out-of-state school programs for the

autistic, and DSS certifies foster care and other child care agencies serving the autistic.

It is possible, and indeed likely, for an autistic person to require services from three of these agencies simultaneously. For example, a school-age autistic client may require a school placement from SED, a foster care placement from DSS, and certain treatment services from OMH or OMRDD. Both the families of autistic, as cited in Chapter 3, and the senior clinical staff of State facilities perceive this fragmentation of service provision for the autistic among four State agencies as a major barrier to access to service and to continuity of service provision.

In summary, these recommendations for future State action to improve the quality of care for the autistic reflect the unmet needs the facilities' representatives perceived, as well as the barriers to addressing these needs that they identified. More clearly, the three issues of better identification of the population, program development, and funding surface again and again. Similarly, the issues of services to families and more specialized staff training are also raised frequently.

Conclusion

In conclusion, the discussion in this chapter indicates that parents who turn to the State's institutional care network for treatment services for their autistic child are likely to be disappointed. State psychiatric, children's psychiatric, and developmental centers offer few specialized inpatient or outpatient services designed for the autistic. Most often the autistic client is shuttled into the regular programming at the center.

In addition, there appears to be little uniformity in the inpatient or outpatient services offered by the various facilities. It is clear that many autistic persons are denied services they might otherwise benefit from due to their place of residence.

Finally, services for families of the autistic are also limited. And, perhaps more importantly, few services are oriented toward the meaningful involvement of families in programming or program planning. This is a particularly disturbing finding in light of the significant body of literature which comments on the successful use of parents as co-therapists.

In short, the Commission's review of the ability of the State's institutional care network revealed serious gaps in its responsiveness to the needs of the autistic and their families. Equally disturbing were the numerous and substantial barriers cited as inhibiting the State from addressing these needs. It appears from the comments of these senior clinicians that significant specialized program development is necessary, and that this development requires that the autistic population be identified and assessed. The need for specialized staff training also is essential if these new programs are to be responsive. All these things cost money and it is hardly surprising that funding for programs for the autistic appeared high on the clinicians' list of barriers, as well as their list of recommendations.

Chapter IV

PERSPECTIVES FROM PROFESSIONAL SPOKESPERSONS ON AUTISM

During the final phase of the Commission's study, staff conducted structured interviews with various New York State professionals who have acquired a reputation in treatment services for the autistic. The Commission hoped that these men and women, many of whom have dedicated their careers to helping individuals with autism, could provide some answers to our unanswered questions and some solutions to unresolved problems.

At the completion of these interviews, staff realized that although our conversations with these spokespersons had broadened our understanding of issues and problems, they did not provide any definitive answers or unilateral solutions. More clearly, it was apparent that while these people helped us to see better the first steps, they did not lead us to any readily apparent destination.

In all, Commission staff interviewed eight such "experts" in the field of autism. No rigid scientific sampling procedure was used to select these men and women. Quite to the contrary, staff asked members of the Board of Visitors Advisory Council to the Commission, various autism advocacy groups, other staff and friends working in the field for nominations. And, a few persons were identified on the basis of their contributions to the autism literature.

Then from a list of about twenty names, eight were selected based primarily on the extent of their work in this field. Staff also attempted to ensure a somewhat balanced sample in terms of the work experiences of individuals. In

the end, the sample included one State facility director, who has developed a model program for autistic adults, three noted researchers and writers in the field, the director of a children's psychiatric clinic, a former director of a Borough District Service Office, and two directors of private psychiatric centers.

The interviews focused on two fundamental questions:

(1) What are the primary issues and problems in providing appropriate services to the autistic?

(2) What do you think should be done by New York State to address these problems and issues?

The interviews themselves varied considerably in length. Some lasted only an hour, while others occupied a full afternoon. But all interviews resulted in significant comment on the two questions cited above.

Issues and Problems

To our question regarding the primary issues and problems in providing appropriate services to the autistic, the spokespersons provided a range of responses. All responses, however, could be grouped in one of the following six broad categories:

(1) the inadequacy and, often, inappropriateness of available treatment services;

(2) the lack of uniform diagnostic criteria;

(3) the extreme variance in current treatment approaches;

(4) the relative absence of services to families;

(5) the lack of responsibility, accountability, and coordination among State agencies involved in service delivery for the autistic; and

(6) the need to strengthen and to unify autism advocacy power base.

All the spokespersons interviewed cited deficiencies in the service delivery system as the most serious problem. Like the families and the senior clinical staff of State facilities, these experts stated that not only was the service system inadequate, but that it was structured so that many autistic persons were receiving inappropriate services.

Specifically, these spokespersons saw a need to develop a full continuum of services for the autistic, a need for weekend and after-school programs, and a need for additional residential treatment programs for children, adolescents, and adults. They also saw a critical need to modify existing services to address better the needs of autistic clients. There was concern among the group that individuals are assigned to programs by diagnoses rather than by need. This method of determining an individual's service needs was seen as particularly unsound in view of the range of functional levels among the autistic population. Generally, the group felt strongly that programs should be tailored to meet the individual needs of autistic clients.

Two other related problems, also cited by a majority of the spokespersons, included: (1) the absence of uniform diagnostic criteria, and (2) the variance in current treatment approaches. As noted in Chapter II, both of these problems arise from the unknown or debated etiology of autism. Without a known cause, autism remains simply a collection of symptoms which can range from moderate to severe. This factor has made the determination of universal diagnostic criteria difficult and has also contributed to the multitude of treatment approaches, each of which is usually based on one or another theory of causation.

The spokespersons pointed out that the absence of clear-cut diagnostic criteria has resulted in a limited

ability to identify the autistic population, which has in turn, resulted in limited service development. One spokesperson specifically raised the problem of early diagnosis of autistic children. He pointed out that the failure to identify these children early, virtually ruled out early intervention therapy, which is so crucial for the habilitation of individuals with autism.

Five of the eight spokespersons interviewed raised problems associated with the wide variance in current treatment approaches to autism. Generally, there was agreement that this variance, together with the considerable debate over the "best" treatment, delayed the development of programs. At the same time, these spokespersons recognized that until more is known about autism that such variance in treatment approaches is both necessary and legitimate. But looking toward the future they saw a need for more stringent evaluations of current programs so that such variance could be overcome based on objective evaluative data in the near future.

Five of the eight spokespersons also cited the lack of services to families as a major problem. All felt that the very basic needs of families - respite services and involvement in their child's program - were not being adequately addressed. Most saw these unmet needs of families as a major factor leading a family to institutionalize their autistic child. There appeared from our interviews to be a need to develop a whole constellation of services for families ranging from home health aide services, to nursery services, to residential respite services, to programs which meaningfully involved parents in planning and implementing treatment.

Another issue which resurfaced in our interviews with "experts" was the confusion and lack of accountability at the State level. Like the families of the autistic, these experts felt that the State bureaucratic "morass" had contributed greatly to the problems of autistic individuals seeking access to services. Comments like, "Everyone is treating the autistic population, OMH, OMRDD, and SED, without any evaluation or coordination," and, "Who is responsible - OMRDD or OMH? OMRDD seems to be doing very little, while OMH facilities still have a significant autistic population," typify the frustration people from the outside and inside feel about the bureaucratic maze of State agencies' involvement with the autistic population.

If there is a rhyme or reason to the efforts of OMH, OMRDD, SED, and DSS, clearly it is not perceived by most persons working in the field. Instead, these people see a confused and unresponsive State structure which serves more as a barrier, than a facilitator to the effective delivery of services. These spokespersons saw the ineffectiveness of the State agencies to work together as inhibiting the identification of existing community-based services, as well as the development of new services.

Finally one spokesperson noted as a major problem the need for a more effective and unified parent advocacy power base for the autistic. This spokesperson felt strongly that an effective advocacy power base was an essential prerequisite to the development of adequate and appropriate services for the autistic.

In summary, the spokespersons generally raised the same issues as the other groups (e.g., families and senior clinical staff of State facilities). Like these other groups, they perceive a need to significantly increase the

services available to the autistic individual and his family and to improve coordination and accountability for services to the autistic at the State level. They also saw as continuing barriers to rapid service development, the absence of uniform diagnostic criteria for autism and the great variance in treatment approaches for this developmental disability.

Next Steps

The Commission staff also asked these experts for their recommendations for State action to address the above problems and issues. Again, the question elicited a variety of responses. These responses related generally to one of three categories:

(1) recommendations for basic applied research on autism;

(2) recommendations for systems change; and

(3) recommendations for services development.

In the area of basic and applied research, three main research areas were identified. These included research to identify the autistic population, research to assess the treatment and care needs of this population, and research to develop a comprehensive multi-disciplinary treatment model for the autistic. In general, the spokespersons advocating for more research agreed that the answers to these basic questions should be the cornerstone for future development of services for the autistic. At the same time, these spokespersons felt that efforts toward immediate program development is essential and should not be delayed awaiting this research.

The spokespersons' many recommendations for systems change focused on the role of State government. Like the families of the autistic, these individuals also believed that accountability for services for the autistic at the State level should be clearly assigned to a single agency. They also saw a need for the State to identify standards of quality care for individuals with autism and to ensure that those standards are met in every region of the State.

Several of the spokespersons also recommended that the State be more flexible in allowing the placement of autistic persons in whatever program best suited their needs regardless of their place of residence or the agency auspices of the program. More clearly, they believe that an autistic individual living in Elmira should not be denied access to a program in Albany, and that an autistic individual should not be denied access to an Office of Mental Health's program simply because he/she is officially under the Developmental Disabilities Act to be served by the Office of Mental Retardation and Developmental Disabilities.

A third category of recommendations, which was addressed by all the spokespersons interviewed, was the development of services. The spokespersons focused on the need for a continuum of services for all ages in every region of the State. The spokespersons also identified many specific services, including:

(1) pre-schools and nursery programs;

(2) school programs;

(3) respite programs;

(4) parent training programs;

(5) community-based small residential programs;

(6) psychopharmocological programs;

(7) family support service;

(8) vocational rehabilitation programs; and

(9) communication skills programs.

Other specific recommendations included the creation of regional centers for the autistic. The primary objectives of these centers would be to ensure that autistic individuals receive appropriate diagnoses and services. These centers would be designed to serve all ages and all functional levels of autistic persons. Similarly, one spokesperson recommended that the State develop special demonstration projects for the autistic. These projects would serve all ages and all functional levels of autistic persons and would have their own facilities (perhaps on a State facility's grounds). Fundamentally, both of these recommendations address the dilemma of many families who cannot find any appropriate services for their autistic children any where in New York State.

In summary, the recommendations for State action of the spokespersons in the field reflect the major problems and issues they identified. They also correspond closely with the recommendations made by families and senior clinical staff of the State facilities. It appears that all concerned with the autistic population see basic issues and problems in the following areas:

(1) diagnosis and identification of the autistic population;

(2) development of appropriate treatment models;

(3) expansion of service delivery to provide a continuum of treatment services for all ages of autistic persons; and

(4) the more definite assignment of accountability and responsibility to a single State agency.

Chapter V

LOOKING TOWARD THE FUTURE: MAPPING THE FIRST STEPS

These findings demonstrate the scope and seriousness of the problems inherent in the service delivery system for the autistic. By all accounts appropriate services are extremely limited and access to these services is often blocked by one or another bureaucratic barrier. The accounts of families of the inadequacy and insensitivity of the service delivery system have been substantiated by both the senior clinical staff of State facilities and reputable spokespersons in the field of autism in New York State.

As Commission staff pursued their research on services for the autistic, it became clear that these problems and issues mandate systemic change. More clearly, it became apparent that meaningful change in the service delivery system would require the joint cooperative effort of the Office of Mental Retardation and Developmental Disabilities, the Office of Mental Health, the State Education Department, and the Department of Social Services. It was also apparent that a single State agency had to be designated the lead agency for services for the autistic and that this agency must assume responsibility and accountability for services for the autistic.

Finally, it also became apparent that the State could no longer put the issue of the autistic on a "back burner". The parents and families are becoming more and more vocal in demanding responsive action to their concerns and needs.

And, meanwhile the identified autistic population in need of services is growing. At present over 20 percent of the State facilities have an inpatient census of over 30 clients evidencing classical autistic behaviors. And, this population reflects only the first generation of adult autistic clients.

Given these imperatives, the Commission on Quality of Care for the Mentally Disabled offers the following recommendations for immediate State action to improve the State's service delivery network for the autistic and their families.

(1) The Office of Mental Retardation and Developmental Disabilities should be designated as the State's lead agency serving the autistic population. As such a lead agency, OMRDD should accept primary responsibility and accountability for ensuring that the service needs of the autistic and their families are met.

(2) A State Autism Task Force should be established as an ad hoc study group of the Developmental Disabilities Planning Council to identify, formally assess the needs of, and plan a course of service development, including residential and non-residential services, for the autistic. The Task Force should also address:

- the service needs and appropriate placement of the adult autistic presently in State Children's Psychiatric Centers;
- the identification of training needs for professional and para-professional staff to serve the autistic;
- the advisability of regional, residential programs for the autistic in lieu of the current dispersal of the population throughout the 51 State facilities;
- the advisability of establishing a Bureau of Autistic Services in OMRDD.

The Task Force should be chaired by OMRDD and should include representation by the Office of Mental Health, the State Education Department, the Department of Social Services, the Commission on Quality of Care, autism advocacy agencies, and parents of autistic individuals. The Task Force should be charged with reporting its findings and recommendations to the Governor within a 12-month time frame.

(3) In the development of new services for the autistic, special consideration should be given to the involvement of parents in the planning process, and in treatment planning and actual programming when they so desire.

(4) Pending the development of appropriate services for the autistic in every region of the State, OMRDD should allow families of autistic children and adults the option of admission to State-operated programs and facilities without regard for regional residency requirements.

(5) The OMRDD should seek federal funds to conduct systematic and comparable bi-annual evaluations of programs serving the autistic. The objective of collecting this evaluative data would be to determine which program models are most responsive to the needs of the autistic. The OMRDD should also continue to access available federal funds for basic research on the causes, nature, and treatment of autism.

(6) The OMRDD should conduct a survey to identify all service providers in the State serving, and/or capable and willing to serve, the autistic. Based on this survey, OMRDD should compile a consumer directory of autism service providers for families of the autistic. In addition, a toll-free hotline to assist families in their search for services should be established by the Office of Mental Retardation and Developmental Disabilities.

(7) The State Legislature should provide special funding for the OMRDD to proceed with an intensive campaign to identify individuals with autism. This campaign should rely on a taxonomy of classical autistic behaviors identified by the above Task Force and should focus on identifying autistic clients in State facilities as well as in community-based services. While the campaign should seek early identification of young children with autistic-like behaviors, caution should be taken not to label children prematurely as "autistic." Rather the identification should serve primarily to assist the child in accessing relevant services to meet his/her needs.

(8) The State Legislature should seriously consider the Office of Mental Retardation and Developmental Disabilities' request for start-up monies for 100 new community residential beds for autistic individuals.

Most of these recommendations can be implemented with no substantial expenditure of new money. The last three recommendations will require new funding. The funding requirements for these recommendations should be determined by OMRDD in conjunction with the State Autism Task Force.

These recommendations reflect the unanimous opinions of the Commission on Quality of Care and the Board of Visitors Advisory Council of the Commission. They are also generally consistent with the implementation of OMRDD's major program initiatives for services for the autistic as specified in their updated Five Year Plan. It is the Commission's sincere hope that the Governor and the Legislature will seriously consider these "first steps" toward building an appropriate and accessible service delivery system for the autistic.

Appendix A

Autism Advocacy Agencies in New York State

HAPPI - Help Autistic People Please, Inc.
200 West 54 Street, #4A
New York, NY 10019
(212) 247-4514
Contact Person: Lila Howard

Nassau Center for the Developmentally Disabled, Inc.
72 South Woods Road
Woodbury, NY 11797
(516) 921-7650
Contact Person: Dr. Michael Oscurchuk

New York State Society for Autistic Children
275 State Street
Albany, NY 12210
(518) 436-0611
Contact Person: Fred Erlich

Special Citizens Futures Unlimited, Inc.
823 U.N. Plaza
New York, NY 10017
(212) 599-3360
Contact Person: Anita Zatlow

S.T.A.R.R. - Services for Treatment of Autism
Respite and Research
(Autistic Habilitation Center - a sub-organization
of S.T.A.R.R. serves autistic adults)
45 Imperial Circle
Rochester, NY 14617
(716) 266-8542
Contact Person: Jean Lake

Appendix B

Responses of:

The Office of Mental Health,
State Education Department,
Department of Social Services,
Office of Mental Retardation
and Developmental Disabilities
to the report

NEW YORK STATE
OFFICE OF MENTAL HEALTH 44 Holland Avenue, Albany, New York 12229

JAMES A. PREVOST, M.D., Commissioner

April 16, 1981

Mr. Clarence J. Sundram
Chairman
NYS Commission on Quality of Care
For the Mentally Disabled
99 Washington Avenue
Albany, NY 12210

Dear Mr. Sundram:

Thank you for forwarding a copy of your agency's report on autism and service to autistic persons in New York State. As you are aware, the legal responsibility for delivery of service to this population lies with OMRDD (as noted in MHL §1.03(22), but due to historical factors approximately 160 autistic persons now reside in OMH children's programs. Despite renewed efforts to resolve issues related to the service needs of these persons and their transfer to OMRDD, many remain in OMH programs because of the unavailability of more appropriate community based services, and space in developmental centers. A series of options are now under discussion in order that an appropriate resolution can be effected by the agencies.

With reference to the recommendations of the report, it is important to note that several of these steps have already been undertaken. The Office of Mental Retardation and Developmental Disabilities has primary responsibility for the care and treatment of autistic persons. In an attempt to adequately plan the transfer of such patients, OMH and OMRDD have begun to jointly evaluate OMH patients for placement with OMRDD. Although your report documents the number of such patients reported to be within OMH programs, it is important to note that the formal diagnosis of Autism did not exist until just recently (i.e. DSM-III), and therefore the number of patients with that diagnosis should not be considered indicative of the extent of this problem. In addition, the term autism has been used as a diagnosis for many patients with mental retardation and autistic features, as the term autism is often more easily accepted.

With one exception, the remaining recommendations can be supported by the Office of Mental Health. However, Recommendation 4 cannot be accepted due to the many legal complications and family hardships it might incur. Any proposal to transfer patients across the state to residential placements will likely result in objections from Mental Health Information Service, advocacy groups and parent organizations. I am sure that you share my concern for the distress parents with autistic children feel, and having their child placed hundreds of miles away will only further their anguish. Alternative proposals have been discussed by OMH and OMRDD to avoid such problems while appropriate community resources are developed.

OMH 26.C1 1

There are several technical points in the report which bear reconsideration, and these include an underestimate of the incidence of autism (approximately 4 cases per 10,000 population yields 7300+ cases, not 5,000). In addition, Dr. Michael Rutter has recently completed extensive research with autistic children concerning its etiology. Your staff may wish to acquaint themselves with that work.

The lack of a full and appropriate continuum of services for autistic patients within the state is a problem with which OMH has wrestled for years. As noted earlier, plans are being developed to resolve these problems, and Mr. Morris, Deputy Commissioner, is coordinating these efforts. Please feel free to contact him if you require additional information on our efforts, and I hope my comments have been helpful to you.

Sincerely,

James A. Prevost

James A. Prevost, M.D.
Commissioner

THE UNIVERSITY OF THE STATE OF NEW YORK
THE STATE EDUCATION DEPARTMENT
OFFICE OF THE PRESIDENT OF THE UNIVERSITY
AND COMMISSIONER OF EDUCATION
ALBANY, NEW YORK 12234

February 23, 1981

Dear Mr. Sundram:

Thank you for your letter and your report "Autism: Looking Toward the Future."

The State Education Department concurs with your report regarding the need for a single designated State agency to coordinate services for the autistic population. Our monitoring activities in local education agencies reflect a serious gap in services as well as a fragmented service delivery system at the State level. With the reorganization of the Department of Mental Hygiene in 1977, it was expected that the transfer of responsibility to the Office of Mental Retardation/Developmental Disabilities for the care and treatment of autistic children would occur. Your report clearly outlines the service delivery problems associated with the lack of a single designated State agency to ensure that appropriate services are available to autistic children.

The State Education Department would support your recommendation for a State Autism Task Force. However, I might suggest that such a role be delegated to OMR/DD's Advisory Council under the rubric of a special subcommittee on autism. This would be consistent with, at least, the current philosophy of moving services to autistic children within the jurisdiction of the New York State Office of Mental Retardation/Developmental Disabilities.

Again, thank you for the opportunity to formally respond to your report.

Sincerely,

Gordon M. Ambach

Mr. Clarence J. Sundram, Chairman
State of New York
Commission on Quality of Care for
the Mentally Disabled
99 Washington Avenue
Albany, New York 12210

cc: Robert R. Spillane

NEW YORK STATE
DEPARTMENT OF SOCIAL SERVICES
40 NORTH PEARL STREET, ALBANY, NEW YORK 12243

BARBARA B. BLUM
Commissioner

February 23, 1981

Dear Mr. Sundram:

I have reviewed your Commission's draft report entitled, "Autism: Looking Toward the Future" and find it to be a pragmatic description of an under-served, needy population.

The report is effective in outlining the non-existence of a single, widely accepted explanation of the cause of autism and the best method for treatment. It would appear to be accurate that program development to serve autistic children has lagged because of the understandable, but problematical, lack of consensus. Likewise, if definitional clarity existed, earlier diagnosis and more effective treatment might result.

In general, this Department is in accord with the recommendations the report makes concerning improving the State's service delivery network for the autistic and their families. I especially support the call for increasing access for parents to get involved in treatment planning and programming for their own children.

The Department would be very pleased to participate in the State Autism Task Force when it becomes established.

Sincerely,

Barbara B. Blum

Hon. Clarence J. Sundram, Chairman
NYS Commission on Quality of Care
for the Mentally Disabled
99 Washington Avenue
Albany, New York 12210

STATE OF NEW YORK
OFFICE OF MENTAL RETARDATION AND DEVELOPMENTAL DISABILITIES

44 HOLLAND AVENUE • ALBANY • NEW YORK • 12229

JAMES E. INTRONE
Commissioner

April 27, 1981

Mr. Clarence J. Sundram
Chairman
Commission on Quality of Care
for the Mentally Disabled
99 Washington Avenue
Albany, New York

Dear Mr. Sundram:

Thank you very much for the opportunity to review your draft report, "Autism: Looking Toward the Future." We have had the opportunity to study its contents, and I would like to share with you our impression and comments.

First, I want to compliment you and your staff for having produced such a comprehensive, high-quality effort. Obviously, we have some reservations about certain of the report findings and recommendations, but the overall effort was most impressive.

You should be complimented, also, on the timeliness of this report. As we are both acutely aware, the Office of Mental Retardation and Developmental Disabilities has over the past five years focused much of its activity on the deinstitutionalization effort. Since much of that effort has been successful, we are now rapidly approaching a period when we can devote additional energy to other priorities and problems. Although constituting approximately five percent of the developmentally disabled, the needs of autistic persons require the same attention as those of the other disabilities to whom we provide service, and it is appropriate that we focus upon meeting their needs.

One further general remark is necessary, and then I will address your findings and recommendations specifically. The history of services to autistic persons, throughout the United States, is replete with examples of new and exciting programs which began without realistic funding allocations, and which ended in disillusion and disappointment for all involved. For the past two years, the Office of Mental Retardation and Developmental Disabilities has requested funding for programs for autistic persons. These requests were not approved in the Legislature. Adequate services for the autistic are expensive. They cannot be provided through the use of existing resources.

Being retarded never stopped anyone from being a good neighbor.

Your finding (number 1, on page xi) concerning lack of information on those who need services, appears to be overstated. We do have clinical data with which to identify the overwhelming majority of persons with autistic symptomatology. The data does appear to be adequate for planning purposes, and indeed, appears in our State Plan. In addition, we have contracted with the State Autistic Society to assist them in further casefinding.

Your finding (number 2, on page xi) concerning effectiveness of, and knowledge about available programs, seem to be oversimplified. There are programs, especially utilizing behavioral modalities, which do appear to have been effective.

Your findings (numbers 5, 6 and 9, on page xii) do appear to accurately depict several programmatic shortcomings.

Your finding (number 7, page xii) regarding staff training, appears to be accurate.

Your recommendation (number 1, on page 46) appears to be fully justified by the findings, and we support it. The Office of Mental Retardation and Developmental Disabilities has for the past two years been willing to accept designation as the lead agency serving autistic persons.

Your recommendation (number 2, page 46) concerning the establishment of a State Autism Task Force has definite merit; however, it should be located in the existing Developmental Disabilities (95-602) Planning Council with special recognition as an ad hoc autism study group. This would take advantage of the Council's charge to assist in the planning for all the developmentally disabled and also the composition of the Council that has representation from the Department of Social Services, Department of Education and others.

We disagree with your recommendation (number 3, page 47) since it would seem to undermine the focus on the New York State Society for Autistic Children as the organization that is currently advising and assisting us in the planning and implementation of autism programs on a statewide and regional basis. Parents as members of this organization or singularly, will be given consideration in treatment planning and actual programming.

Your recommendation (number 4, page 47) concerning admission and transfer among programs, considering New York State as a single catchment area until new services can be developed locally, is also an idea which we will support.

Your recommendation (number 5, page 47) that we seek Federal funds to perform bi-annual program evaluations, is also supported, although we do assert that more is known about adequate programming than the report indicates.

Your recommendation (number 6, page 47) concerning developing a directory of autism services is also supported. Many of the agencies listed will undoubtedly also be serving other developmentally disabled persons as well.

Your recommendation (number 7, page 48) has already been implemented through the Office of Mental Retardation and Developmental Disabilities' implementation of the Developmental Disabilities Information System, and through funding the State Autistic Society's outreach efforts.

Your recommendation (number 8, page 48) concerning Legislative support for start-up monies for 100 new community residential beds for autistic individuals is enthusiastically supported by the Office of Mental Retardation and Developmental Disabilities.

In summary, your study has articulated and clarified a number of the problems inherent in a small disability group with an extremely complex etiology and treatment regimen. As such, it is of distinct value to this agency in its efforts to plan for the provision of services to the autistic individual.

Thank you again for the opportunity to comment on the report.

Sincerely,

James E. Introne
Commissioner

STATE OF NEW YORK
COMMISSION ON QUALITY OF CARE
FOR THE MENTALLY DISABLED
99 WASHINGTON AVENUE
ALBANY, NEW YORK 12210

CLARENCE J. SUNDRAM
CHAIRMAN

I. JOSEPH HARRIS
MILDRED B. SHAPIRO
COMMISSIONERS

May 29, 1981

Hon. James E. Introne
Commissioner
Office of Mental Retardation
and Developmental Disabilities
44 Holland Avenue
Albany, NY 12229

Dear Commissioner Introne:

Thank you very much for your overall positive response to the Commission's report, "Autism: Looking Toward the Future." The purpose of this letter is to respond to some of the points of disagreement you raised regarding certain findings and recommendations of the report and to attempt to reach a meeting of the minds before the report goes to print.

Your response, together with the responses of the Office of Mental Health, the State Education Department, and the Department of Social Services, will be included as appendices to the final report. As this letter indicates, the Commission sees merit in two of the points of disagreement you raised in your response. However, for the reasons described below the Commission disagrees with several of the other points raised and suggests that you may wish to reconsider these aspects of your response.

Each of the points of disagreement which you raised regarding the report's findings and recommendations are presented below. The report's statement is presented first, then your response, and finally the Commission's rebuttal to your response.

I. Report Statement:

The autistic are a small minority in a service delivery system that is driven by the needs of other larger and better organized groups of developmentally disabled and their families. Their special needs

have been largely ignored by the system. At present, it is impossible to accurately identify or even closely approximate the number of persons with classical autistic behaviors who are in the service delivery system. (P. xi).

Your Response:

Your finding (number 1, on page xi) concerning lack of information on those who need services, appears to be overstated. We do have clinical data with which to identify the overwhelming majority of persons with autistic symptomatology. The data does appear to be adequate for planning purposes, and indeed, appears in our State Plan. In addition, we have contracted with the State Autistic Society to assist them in further casefinding.

Commission's Response:

Based on further discussion between Commission staff and John Jacobson of your staff and a review of the two casefinding grants awarded to the New York State Society for Autistic Children, The Commission agrees that the present language of the last sentence of this finding may be overstated. This sentence will be stricken from the final report and replaced by the following three sentences:

At present, it is impossible to accurately identify the numbers of persons with classical autistic behaviors in need of services in New York State. Less that 20 percent of the estimated total autistic population of 5000 individuals have presently been identify by OMRDD. The vast majority of the unidentified autistic are suspected to be either unserved or underserved by the present service delivery system.

II. Report Statement:

There is no accepted theory of etiology of or diagnosis for autism and therefore various treatment modalities, with varying assumptions about autism, are being used with little evidence of differences in therapeutic effectiveness, regardless of therapy chosen. (p. xi).

Your Response:

Your finding (number 2, on page xi) concerning effectiveness of, and knowledge about available programs, seem to be oversimplified. There are programs, especially utilizing behavioral modalities, which do appear to have been effective.

Commission's Response:

The Commission feels that your response to this report finding does not reflect the substance of the finding. More clearly, the finding does not state or imply that present therapies are ineffective, rather it only comments on the lack of substantial evidence regarding the differences among the present therapies' effectiveness. The body of the report does comment on the alleged effectiveness of several therapies and specifically cites the slight evidence favoring behavior modification programs (see pp. 6-11). Based on these comments, it is our view that the report finding does not require revision.

III. Report Statement:

A State Autism Task Force should be established to identify, formally assess the needs of, and plan a course of service development, including residential and non-residential services, for the autistic. The Task Force should also address:

- the service needs and appropriate placement of the adult autistic presently in State Children's Psychiatric Centers;
- the identification of training needs for professional and para-professional staff to serve the autistic;
- the advisability of regional, residential programs for the autistic in lieu of the current dispersal of the population throughout the 51 State facilities;
- the advisability of establishing a Bureau of Autistic Services in OMRDD.

The Task Force should be chaired by OMRDD and should include representation by the Office of Mental Health, the State Education Department, the Department of Social Services, the Commission on Quality of Care, autism advocacy agencies, and parents of autistic individuals. The Task Force should be charged with reporting its findings and recommendations to the Governor within a 12-month time frame.

Your Response:

Your recommendation (number 2, page 46) concerning the establishment of a State Autism Task Force has definite merit; however, it should be located in the existing Developmental Disabilities (95-602) Planning Council with special recognition as an ad hoc autism study group. This would take advantage of the Council's charge to assist in the planning for all the developmentally disabled and also the composition of the Council that has representation from the Department of Social Services, Department of Education and others.

Commission's Response:

The Commission is pleased that you agree with the merit of establishing a State Autism Task Force and has no problems with the establishment of such a group as an ad hoc study group of the Developmental Disabilities Planning Council provided that:

(1) the charge to the group remains consistent with that recommended in the report;

(2) the composition of the group remains consistent with that recommended in the report (the Commission is especially concerned that autism advocacy agencies and parents of autistic individuals be represented in this group); and

(3) the group reports its findings and recommendations to the Governor within a 12-month time frame.

If OMRDD can agree to these provisions, this report recommendation will be revised to state that the State Autism Task Force should be an ad hoc study group of the Developmentally Disabilities Planning Council.

IV. Report Statement:

The OMRDD should immediately establish a Families of Autistic Clients Advisory Council in every region (County Service Group) to advise and assist the agency in planning and implementing regional autistic family services. In addition, in the development of new services for the autistic, special consideration should be given to the involvement of parents in the treatment planning and the actual programming when they so desire.

Your Response:

We disagree with your recommendation (number 3, page 47) since it would seem to undermine the focus on the New York State Society for Autistic Children as the organization that is currently advising and assisting us in the planning and implementation of autism programs on a statewide and regional basis. Parents as members of this organization or singularly, will be given consideration in treatment planning and actual programming.

Commission's Reponse:

The Commission commends the efforts of OMRDD to work closely with the New York State Society for Autistic Children. However, the Commission does not believe that this relationship is adequate to provide meaningful input from families of the autistic in the planning and development of services for the autistic on a regional level. As you are aware, parents of the autistic have largely shouldered the burden of locating and developing services for their children and their substantial expertise in this area is well documented in the literature. As you are also aware, the State Society for Autistic Children is but one of several advocacy groups in the State dedicated to the autistic (see appendix A of the report). For various ideological and other reasons these groups have not chosen to affiliate with the State Society. As a result the State Society for Autistic Children represents only a partial perspective of the autism constituency.

Given these reservations, the Commission is not in agreement that OMRDD's informal working relationship with the New York State Society for Autistic Children is sufficient to provide adequate input from the families of the autistic in the planning and development of services at the regional level. The Commission believes that, especially at this time, some formal family advisory structure must exist at the county service group level to provide advice to OMRDD as the agency initiates its effort to develop services for this long neglected group of developmentally disabled people. The Commission will, however, consider other alternative suggestions you may have for establishing such a formal structure, perhaps in conjunction with the New York State Society for Autistic Children.

V. Report Statement:

The State Legislature should provide special funding for the OMRDD to proceed with an intensive campaign to identify individuals with autism. This campaign should rely on a taxonomy of classical autistic behaviors identified by the above Task Force and should

seek early identification of young children with autistic-like behaviors, caution should be taken not to label children prematurely as "autistic." Rather the identification should serve primarily to assist the child in accessing relevant services to meet his/her needs.

Your Response:

Your recommendation (number 7, page 38) has already been implemented through the Office of Mental Retardation and Developmental Disabilities' implementation of the Developmental Disabilities Information System, and through funding the State Autistic Society's outreach efforts.

Commission's Response:

Based on Commission staff discussions with John Jacobson of your staff and the Commission's review of the two grants awarded to the New York State Society for Autistic Children, the Commission finds that the present efforts referenced in your response fall seriously short of our stated recommendation. More clearly, according to Mr. Jacobson, OMRDD has surveyed approximately 80 percent of the persons in the OMRDD service delivery system to identify the autistic. This survey, however, only identifies individuals who already carry an autism diagnosis and has resulted in identifying only slightly over 900 individuals. According to OMRDD's own estimate (cited in the State Plan) this figure represents only 20 percent of the State's total autistic population of 5000.

When Mr. Jacobson was questioned about this discrepancy, he offered two noteworthy explanations. First, he pointed out that since there are only limited services for the autistic, many individuals who may evidence classical autistic behaviors are not so diagnosed because such a diagnosis does not aid in service placement and may, in some cases, even be detrimental to service placement. Secondly, he pointed out that only recently has OMRDD recorded the diagnosis of autism. Mr. Jacobson also pointed out that many autistic in the SED and DSS service delivery system are not presently identified.

The Commission's review of the two casefinding grants awarded to the State Society for Autistic Children reveals that these grants, while commendable in their objectives, lack the necessary fiscal resources and sophisticated methodologies to achieve their purposes.

In summary, the present efforts for identification of the autistic have identified less than 20 percent of the autistic population in New York State. And, perhaps most importantly,

this identified population is limited largely to those autistic already diagnosed and receiving services. Based on these findings, the report's recommendation for a Legislative appropriation to fund an identification campaign for the autistic will remain in the final report. We hope you will see fit to support it as a means of augmenting the initiatives already undertaken.

I hope this letter has been helpful to you in clarifying the Commission's position with regard to your response. I would appreciate receiving your comments and/or an amended response which you would wish to have included in the report, within two weeks.

Thank you for your further attention to these issues.

Sincerely,

Clarence J. Sundram
Chairman

Attachments

STATE OF NEW YORK
OFFICE OF MENTAL RETARDATION AND DEVELOPMENTAL DISABILITIES

44 HOLLAND AVENUE • ALBANY • NEW YORK • 1222

JAMES E. INTRONE
Commissioner

July 21, 1981

Mr. Clarence J. Sundram
Chairman
Commission on Quality of Care for the
Mentally Disabled
99 Washington Avenue
Albany, New York 12210

Dear Mr. Sundram:

I appreciate your staff's thorough review of the comments offered in my previous letter. Although there still appear to be areas of contention, I am sure that we can reach agreement through further dialogue. I have reviewed your letter with my staff, and we would like to offer some additional information which may help clarify our previous statements.

Point I: That It Is Impossible to Estimate the Number of Autistic Persons Who are Receiving Services.

The projection of 5,000 individuals that is used in the State Developmental Disabilities Plan resulted from a weighted average of prevalence rates reported in the literature. It should be kept in mind that it is a statistical projection and that it represents persons of all ages. Additionally, it is not a firm figure because as you can imagine, different prevalence rates, as reported in the literature, produce varying projections. For example, when some of these rates are applied against the 1980 New York State population, varying projections occur: 2.0/10,000 produces 3,500 persons; 2.8/10,000 produces 4,900; and 5.0/10,000 produces 8,750. Furthermore, when the proportions of persons who would be projected to have "classical" autism is examined, the picture is further complicated: .7/10,000 produces 1,225 while 3.0/10,000 produces 5,250.

It is generally difficult, if not impossible, to survey and gather information about people with a given disability that confirms prevalence rates for a low-prevalence disability. Historically, the design of sample surveys to estimate the occurrence of diagnosed cases of rare diseases in the population has presented two major difficulties: (a) large sampling errors usually associated with survey estimates of rarely occurring events and, (b) potentially large non-sampling errors associated with diagnostic information reported in surveys.

Being retarded never stopped anyone from being a good neighbor.

However, we have made attempts to identify some of the people we expect to make up that 5,000 figure, although we have not identified all, we feel that we know about a reasonable proportion of that number.

(1) We estimate that the greater proportion of adults with severe autism are in OMH facilities. Traditionally, adults with autism have been served by OMH. Standard diagnostic practice has been to rediagnose non-retarded autistic adolescents as schizophrenic when they reach maturity - this could account for as many as 51% or 2,479 of the 4,900 persons the Plan projected as disabled by autism based on the 1980 census.

OMH has also reported serving 170 persons with autism who are under 21. It is also probable that some persons with autism are served by clinics and community mental health centers. No reporting systems now efficiently pick up information which could be used to identify this group.

(2) A proportion of the children have been identified by SED. The SED has reported serving approximately 1,600 persons disabled by autism. However, we found that DDIS information could be obtained on only 265 of these individuals due to withdrawal of support for information gathering by SED.

(3) It is probable that some proportion of severely and profoundly mentally retarded persons served in developmental centers are autistic, but are undiagnosed as such due to very severe or profound retardation which predominantly characterizes their functioning. This cohort, and similar individuals in intensive treatment programs in the community are probably not underserved because of the intensity and individually tailored nature of program services.

(4) To date, we have identified approximately 1,000 persons with autism through the DDIS. This includes persons in institutional settings as well as those living in the community.

In sum, the persons not reflected in the DDIS are in most part (1) adults probably served in residential facilities operated by OMH, and (2) children served in SED programs. When known or suspected cases are taken into account according to present service auspices (assuming that OMH serves 75% of adults who have had changed or historically different diagnoses) 3,730 of 4,900 projected persons can be identified by auspices for a gap of 1,200 rather than 4,000 persons to be identified. Again, we must keep in mind that the 5,000-person figure is only an estimate and should be seen as a goal for which we should strive in identification of individuals. Consequently, we do not believe that it is fair to say that there are significant numbers of persons unaccounted for. We would, however, say that they may be underserved.

Point II: That There is Little Agreement in Treatment Methods

Understanding of etiological factors in autism may be likened, in part to those of other disorders which are markedly more prevalent, for example, schizophrenia. While schizophrenia has been recognized as a specific class of condition for much longer than autism, reviews of the literature disclose high level of disagreements in the relative contributions of genetic, general organic, and psychosocial factors to expression of the condition among individuals and groups. Research into the etiology of autism has been hampered by (1) the low prevalence of the conditions which hinders collection of data on an adequate sample of individuals to permit drawing firm conclusions, and (2) changing diagnostic criteria over the past two or three decades. However, it is notable that, with the advent of increasingly sophisticated technology, neurologic factors appear to be more apparent in the etiology of autism and other poorly understood conditions.

Regarding diagnosis, if one reviews the definitions as offered by NSAC and Rutter in the Journal of Autism and Developmental Disabilities, as well as the DSM-III, six principal areas of functional anomaly may be noted: onset pattern, social impairment, language/communication, response to stimuli, maintenance of environment, and inconsistent developmental patterns. While emphasis of the diagnostic significance of each of those may vary among definitions, nevertheless NSAC and DSM-III definitions both target each of these areas and the Rutter definition covers five of them. In light of the low prevlence rate of the condition, these parallels are surprising and one might argue that diagnosis should be relatively good, given few barriers to accuracy. One barrier is that the psychiatrist or psychologist may never see a person on a professional basis who is appropriately diagnosed as autistic - it is an unfamiliar syndrome to many. A second consideration is the barrier presented to diagnosis by a non-verbal individual who may be mentally retarded, or may be both mentally retarded and autistic; however, only the behavioral functioning of the individual will permit any decision to be made in this area.

In terms of effectiveness of treatment methods, we note that there is no significant body of literature which suggests differentiation of therapeutic effectiveness, apart from symptomatic relief of manic-depressive involvement through medication and similar findings for some other conditions, for any major condition which pervasively limits a person's ability to function. The controversies cited in your report can be equally applied to the major organic/psychogenic pervasive disorders. The question also exists as to whether you would "treat" a profoundly retarded person with autism differently than one without autism.

We would recommend the report statement could be modified to reflect the fact that this same sort of controversy exists around other conditions and is perhaps generally reflective of the state of the art. Our concern is that your finding reflects a strong negative connotation that is targeted at autism services; we believe this same connotation applies to other state of art therapies for specific disorders and conditions.

Point III: That is the Council Take a Role in the Autism Task Force

We feel that the Developmental Disabilities Planning Council, with guidance, would agree to the conditions as outlined in your response and meet the time frames proposed. We would agree to take the chair of such ad hoc study group and participate fully.

Point IV: That Special Advisory Committees be Set Up.

Contacts with local DDSO's and BDSO's in the areas associated with the five non-NYSSAC advocacy agencies have disclosed active, ongoing involvement by district offices with each of these agencies. Since these relationships provide an immediate mechanism for input to the local planning process, these groups have an impact upon program development in their geographic areas. In such a context, the formation of an advisory council of the type proposed may represent bureaucratic redundancy.

Furthermore, the significant focus of responsibility in each county is the Community Services Board. These Boards are relegated a wide range of responsibilities under the Mental Hygiene Law. One responsibility is planning for services. We have, and will continue to, insist that the Boards include autistic persons within their aegis. We have also provided supports to parents of, and providers for, autistic individuals to gain appointments to the Boards. Since the need for services for autistic individuals transcend what the office can provide, the logical solution is to increase the emphasis on local coordinative bodies, such as the Boards, to include all apsects of services needs for autistic persons as part of the local services system.

We view the creation of advisory boards to our County Service Groups as not being the proper means to influence service delivery. We have working relationships between our district offices and local autistic groups and intend to strengthen these. Our recommendation is that the Commission's Report include a reference to the Community Services Boards. These Boards should receive your support to clearly recognize their responsibility in including the needs of autistic persons in their planning and local services coordination.

Point V: That Special Funding be Provided for Identification.

We cannot quarrel with a recommendation that would spur the legislature to provide funding for a special effort. Certainly, should the legislature offer funds for a Statewide identification process, we would cooperate fully and expect that the information would benefit not only OMRDD, but other state agencies as well.

We appreciate the opportunity to further clarify our thoughts on the Commission's recommendations. I trust that should you have further comments, you will not hesitate to let me know.

Sincerely,

James E. Introne
Commissioner

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